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# Alpha Thalassemia



## Information for parents about hemoglobin Bart's and alpha thalassemia

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### **What is hemoglobin?**

Hemoglobin is the part of blood that carries oxygen to all parts of the body. Genes that we inherit from our parents determine what type of and how much hemoglobin we have.

### **What is alpha thalassemia?**

Hemoglobin is made up of many different parts, including alpha globin. Alpha globin is produced by four genes and when any of those genes are not working properly the body makes less hemoglobin. This is called alpha thalassemia and occurs in four different forms, depending on the number of genes not working. One form of alpha thalassemia cannot turn into another kind. Your child will have that form for his or her entire life.

### **Why was my child screened for alpha thalassemia?**

The Newborn Screening Program screens all infants born in Washington State for certain disorders, including hemoglobin disorders. A small amount of blood was collected from your infant's heel and sent to the State Laboratory for testing. That testing found a higher than normal level of hemoglobin Bart's, a protein that is made when alpha globin genes are not working properly.

### **What happens when one gene for alpha globin is not working?**

A person who has one of the four alpha globin genes not working is called a silent carrier. This form of alpha thalassemia does not cause any major changes in the hemoglobin or any health problems.

### **What happens when two genes for alpha globin are not working?**

A person who has two of the four alpha globin genes not working has alpha thalassemia trait. This form of alpha thalassemia causes only small changes in the hemoglobin and does not cause any health problems.

### **If one or two non-working genes for alpha globin do not cause any health problems, why do I need to know that my child has alpha thalassemia?**

Although one or two non-working alpha globin genes do not cause any health problems, you and your baby's doctor should know that it can cause a mild anemia (low number of red blood cells). It is also important to know about your child's alpha thalassemia status because future children in your family, or other family members, may be at risk for more serious forms of alpha thalassemia, which are described on the next page. Also, people with the silent carrier form or alpha thalassemia trait can pass the gene(s) to their children.

### **What happens when three or four genes for alpha globin are not working?**

If a person has three non-working genes, it will result in hemoglobin H disease. Hemoglobin H disease can sometimes cause serious health problems due to moderate or marked anemia and should be followed regularly by a doctor. People with four non-working genes are unable to produce the hemoglobin needed to live. This is called alpha thalassemia major. This is not what your child has. This form causes death in the affected individual before or soon after birth. If your doctor or genetic counselor feels that you are at risk for having a baby with either of these forms of alpha thalassemia, they will provide you with more information.

### **What do I do now?**

Your baby's doctor may do more testing on your baby to clarify which form of alpha thalassemia your baby has (whether one or two genes are not working). This will involve drawing a small amount of blood from your baby. It is also recommended that you and your partner have testing done to determine your hemoglobin status. This would provide information on your chances of having a future child with a more serious form of alpha thalassemia. To have this testing done, talk to your health care provider or one of the genetic counselors listed on the back of this pamphlet. You may also want to share this information with the rest of your family. They may be interested in finding out their hemoglobin status as well.

### **What can I do if I have more questions?**

If you have more questions, you can talk to your child's health care provider or you can contact the Newborn Screening Program using the information below.

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Shoreline, WA 98155  
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Email: [NBS.Prog@doh.wa.gov](mailto:NBS.Prog@doh.wa.gov)  
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